# Folic Acid to Prevent Neural Tube Defects:

# An Intervention for Hispanic Families

By

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# Abstract

Congenital malformations are one of the leading causes of infant morbidity and mortality in the United States, and neural tube defects comprise a significant number of those malformations. Neural tube defects (NTD) are caused by a lack of closure of the neural tube at various levels of the spinal cord during development. About one child in 1000 is born each year in the United States with some type of NTD. The incidence of NTD is higher among Hispanics. Approximately 50-70% of NTD can be prevented by the ingestion of at least 0.4 milligrams of folic acid prior to and just after conception. The main goal of this program plan is to increase awareness of neural tube defects and their prevention with folic acid. The targeted group will be Hispanic women of childbearing age who reside in a rural North Carolina county and use the county health department as their usual source of care. The program will focus on educating the women and their families about the importance of supplementation of a healthy diet with folic acid, in order to prevent neural tube defects in their children. It will integrate well-known health behavior theoretical models with a culturally specific intervention. Evaluation of the program's success will include analysis of pre-intervention and post-intervention surveys to determine increases in knowledge and changes in behavior in an intervention group versus a comparison group.

# Introduction

Congenital malformations are one of the leading causes of infant morbidity and mortality in the United States, and neural tube defects (NTD) comprise a significant number of those malformations.[1] Neural tube defects usually occur during the 18th to 28th day of pregnancy when the early spinal cord is forming. They are caused by a lack of closure of the neural tube at various levels of the cord. The most common types are anencephaly, where the top part of the brain does not form, and myelomeningocele (Spina bifida), where the bottom part of the spinal cord outpouches into a defect in the skin. Children with anencephaly are usually stillborn or die soon after birth. Those with Spina bifida usually survive, but many have severe disabilities, including lower extremity paralysis, bladder-bowel incontinence, and endocrine disorders. About one child in 1000 is born each year in the United States with some type of neural tube defect.[1] Approximately 50-70% of NTD can be prevented by the ingestion of at least 0.4 milligrams (400 micrograms) of folic acid prior to and just after conception. Because many pregnancies are unplanned and many women do not know they are pregnant for several months, the Centers for Disease Control and Prevention recommends that folic acid be taken by all women of childbearing age, regardless of their intent to get pregnant.[1] (See Figure 1.)

The state of North Carolina has one of the highest rates of NTD in the country with four affected pregnancies per week, only half of which result in live births.[2]. This corresponds to a rate of 9.7/ 10,000 live births. The North Carolina Birth Defects Monitoring Program was created to collect information on birth defects,

locate resources and support for affected families, provide education for the public and providers, and decrease the incidence of birth defects.[2] In January 1999 the Centers for Disease Control and Prevention, the March of Dimes, and the National Council on Folic Acid launched a national campaign to educate women about the etiology and prevention of birth defects. Many states have implemented similar programs in order to obtain accurate and timely information about birth defects.

The main goal of this program plan is to increase awareness of neural tube defects and their prevention with folic acid supplementation. The targeted group will be Hispanic women of childbearing age who reside in Columbus County and use the Columbus County Health Department as their usual source of care. The program will focus on educating women and their families about the importance of supplementation of a healthy diet with folic acid, in order to prevent neural tube defects in their children. The program will integrate well-known behavioral models with a culturally specific intervention. Evaluation of the program's effectiveness will include surveys to determine increases in knowledge of folic acid and its benefits and changes in behavior to include taking adequate amounts of folic acid.

## The Site

Much of the public health programming in North Carolina occurs at the local level. North Carolina has 100 counties with 86 health departments. Columbus County Health Department, the site of the intervention, is located in Whiteville, North Carolina. According to the 2000 United States Census, Columbus County had a population of 54,749.[3] Whiteville is its largest town and is the county seat. The largest industry is manufacturing, followed by government and retail. The county has low rates of education and income. Only about 60% of adult residents are high school graduates and 9% have college degrees. In 1998 the unemployment rate was 7.6%, and the median family income was $29,800 in 1999, ranking Columbus County 88th among NC counties.[4]

Demographically, Columbus County is becoming increasingly diverse. According to the 2000 Census, 63% of the residents are white, 31% are black, 3% are Native American, and 2.3% are Hispanic.* The Census counted over 1200 Hispanics residing in Columbus County, although Hispanic community leaders estimate that the true number is much higher.[5] The Faith Action, a private group that estimates the number of Hispanics/Latinos in North Carolina counties each year, estimates the number to be 1755.[6] This large number mirrors the explosive increase in Hispanics in the state with 378,963 people documented by the 2000 Census compared to only 76,726 in 1990, a 500% increase.[3]

* The terms Hispanic and Latino/Latina will be used interchangeably to denote descendents from Mexico, Central and South America, and the Caribbean and people whom self-identify as Hispanic/Latino.

This increasing diversity has had a significant impact on the delivery of health care services in the county and the state. The Columbus County Health Department (CCHD) has responded to these changes by delivering more culturally competent care. In addition to their usual services, the health department staff has focused on providing outreach for Hispanics living in the county. CCHD has two full time interpreters on staff and one migrant outreach worker. The health department provides care for many of the county's Latino residents; however, they have not yet been able to quantify how many people they serve.[5] Using the Census data and the Faith Action data, a conservative estimate of 1,600 Latinos residing in the county can be made. If only half of these residents used CCHD, it would serve about 800 Hispanic persons per year.

## Needs Assessment

The State Division of Public Health requires all North Carolina health departments to conduct a needs assessment of their county every two years.[5] The latest assessment for Columbus County began in December 1999. The needs assessment information that follows is based on secondary data compiled by the North Carolina State Center for Health Statistics and other national sources. Where there were insufficient or missing data, information was obtained from peer-reviewed journals or national databases. Suggestions for compiling additional primary data through community assessment are provided.

As described earlier, birth defects are a pervasive problem in North Carolina. The overall birth rate in the state was 14.3/1000 persons with a NTD rate of 9.7/10,000 live births.[2,7] The birth rate for minorities was 16.1/1000 persons. In 1999 there were 838 births in Columbus County, resulting in a birth rate of 16.0/1000 persons. County information is not available specifically for NTD, but there were 23 cases of congenital malformations documented at Columbus County Hospital in 1997.[7] This number is difficult to interpret since many of the affected infants are sent to tertiary care centers throughout the state soon after birth.

Most students of public health are familiar with the epidemiologic paradox as it applies to Hispanics. They have been found to have better birth outcomes with less infant mortality than other racial groups in this country, despite lower rates of prenatal care.[8] Latinas are 3.5 times more likely to have late or no prenatal care when compared to non-Hispanic whites (11.0% and 3.2% respectively), about the

same rate as blacks (10.7%). Among Hispanics, Cuban-Americans have the lowest rate of late or no prenatal care (2.4%), while Mexican-Americans have the highest rate (12.2%)[8]. Despite such disparities in prenatal care, the infant mortality rate among Latinas is only 7.5/1000 live births, compared to 7.1/1000 live births for whites[9]. The rate for blacks is much higher at 17.5/1000 live births. Latinas also have fewer low birth weight babies, with Mexican-Americans having the lowest percentage (5.6%) and Puerto Ricans having the highest (9.4%). This compares to 5.7% and 13.6% low birth weight babies for whites and blacks, respectively.[9] The reasons for this paradox are not known. However, Latinas are less likely to smoke, drink, or abuse drugs during pregnancy when compared to other women, which may account for some of the difference. Interestingly, as with many other health outcomes for immigrants, the rate of infant mortality increases with subsequent generations born in the United States.[9]

Although Latinas have low rates of infant mortality and low-birth weight babies, they have some of the highest rates of neural tube defects. The general population rate in the United States for NTD (anencephaly and Spina bifida) was 6 cases per 10,000 live births in 1996.[10] Based upon a study that included surveillance from six different states, the rate of neural tube defects for Hispanics was 6.1/10,000 live births, compared to 4.5 and 4.1/10,000 live births for whites and blacks in the same study.[11] Much of the discrepancy among these rates occurs due to lack of inclusion of statistics from births that were terminated or died prior to 20 weeks of gestation. In a study conducted at the Texas-Mexico border that included live births, still-births, and abortions, the rate of NTD for

Hispanics was 14.9/10,000 live births.[12] This high rate is probably due to the large number of Mexican-Americans in the sample, who are known to have the highest rates of neural tube defects among Hispanics. In fact, Mexico has one of the highest rates of NTD in the world (33/10,000 births), second only to Northern China (57/10,000 live births). The reason for this disparity is thought to be due mostly to environmental and nutritional factors. [13]

Although the exact rate for NTD is not known for Columbus County nor for the Hispanics that reside there, the health department decided to take a proactive role in developing a program to prevent birth defects, in accordance with Healthy People 2010 and the national campaign.[1, 10] They already have a general campaign for NTD prevention in the health department. I decided to focus this program on Hispanics as a target group because of their elevated incidence and prevalence of NTD, and because most of the Hispanics in Columbus County are immigrants from Mexico. I also wanted to implement a small culturally specific campaign for two reasons: (1) to learn successful culturally specific programming tactics that can be used for other interventions and (2) to learn strategies for successful programming for other groups in Columbus County. The intervention will focus on educating Hispanic women about the benefits of folic acid in preventing neural tube defects and on changing their behavior to include increasing their folic acid intake.

The stakeholders include the families served by the intervention, as well as any unborn children. Also, the entire population of Hispanics in Columbus County not served by the health department could potentially benefit, depending

upon the success of the program. The health department staff would also benefit from learning more about the Hispanic community and from providing a service that will bring more people into the clinic. Other stakeholders include other health care providers in the community, county officials, and leaders within the Hispanic community.

**Recommendations for Additional Needs Assessment**

The health department's current needs assessment would be enhanced by further study of the Hispanic community in Columbus County. This would involve collecting primary data from several sources. The most accessible sources would be key informant interviews within the health department. The interpreters, nurses in all departments, front office staff, and WIC staff could be interviewed about the Hispanics that visit the health department. Other key informants would be leaders in the community, including elders, ministers, health care providers, small business owners, or other designated individuals.

Interviews could also be conducted in Spanish or English with the Hispanic patients that visit CCHD. Valuable information would include usual sources of care besides the health department; social gathering spots such as grocery stores, clothing stores, and community centers; home remedies for common illnesses; usual dietary and exercise patterns; and media sources used by Hispanic residents.

The health department could also conduct focus groups with Hispanic families and discuss above questions, as well as inquiring about their perceived health needs. These focus groups would need to be initiated and led by bilingual or

monolingual Hispanic community leaders in order to encourage participation. They should be conducted in Spanish, if the majority of participants speak Spanish, and translated for English speaking participants.

Surveys are another possible way to gather information. Suggestions for systematic and valid surveys in Spanish could be obtained from the North Carolina State Division of Public Health, Office of Minority Health or the Centers for Disease Control and Prevention. These suggestions would help the CCHD improve their assessment of the health of their Hispanic patients.

## Theory/Model

The following theories and models will be utilized in designing an intervention for Hispanic women of childbearing age: the Health Belief Model, the Persuasion Communication Model, and the Lay Health Advisor approach. The Health Belief model (HBM) includes four components – perceived susceptibility, perceived severity, perceived benefits, and perceived barriers.[14, 15] This model is helpful in that it explains reasons for a person engaging in a certain health-related behavior. Having originally been developed in the 1950's to explain why people did not participate in tuberculosis screening, the HBM is particularly well-suited for explaining the adoption of preventive health behaviors, such as supplementation of the diet with folic acid.[16] If a woman thinks that she has low susceptibility to birth defects, that birth defects are not very severe, or that there is no real benefit in taking folic acid, she is much less likely to take a supplement. Generally, if she perceives a benefit, she is more likely to take folic acid.[16] The limitation of this model for intervention development is the absence of specific methods for making behavior changes.[17]

The Persuasion Communication Model (PCM), developed by W.J. McGuire in 1985, provides steps for eliciting a behavior change through health education. The PCM stages include: exposure to the message, attention to the message, comprehension of the arguments and conclusions, acceptance of the arguments, retention of the content resulting from information integration, and attitude change.[17, 18] McGuire also developed a matrix that includes the steps and intervention possibilities. The matrix takes the steps toward behavior change

farther. They include attention, comprehension, attitude, social influences, self-efficacy, behavior, and maintenance.[18] This model seems well suited to an intervention that educates women about folic acid. It takes into account that women may be at different stages of knowledge and may require different interventions based upon their stage. (See Figure 2.)

The lay health advisor approach has been used since the 1960s to provide linkages between communities and health care centers.[19] Also known as community health workers, promotoras, or natural helpers, lay health advisors (LHA) have been defined as "an individual who is indigenous to his/her community and consents to be a link between community members and the service delivery system."[20] Intervention strategies employed by LHA range from formalized paraprofessional strategies, where the LHA is an employee of the agency, to natural helping strategies, where the LHA has no formal ties to the agency and answers only to the community.[21] The LHA approach has been used to improve access and use of services and to change knowledge and behavior.[22] The effectiveness of this approach was reviewed in 2002 by Susan Swider with variable results.[19] In the studies reviewed, she found evidence for the effectiveness of LHA to increase access to care, but very limited evidence supporting changes in the client's knowledge and behavior by LHA. She concluded her review by calling for more rigorous studies on the LHA approach.[19]

# Literature Review

Supplementation of the diet with folic acid to prevent neural tube defects is recommended by the CDC.[1] Effective in the 1998, the Food and Drug Administration ruled that foods labeled "enriched" must be fortified with folic acid. These include cereals, grains, and breads. Although some foods naturally contain folic acid (papaya, raspberries, beans, greens, nuts, liver), the "enriched" foods and vitamin supplements are more easily absorbed and are a more reliable source of folic acid.[23] Therefore, the CDC recommends a single folic acid supplement or multivitamin with 400 micrograms of folic acid or a cereal with 100% of the Recommended Daily Value of folic acid, in addition to a healthy diet.[1]

A landmark prospective cohort study confirmed the effectiveness of folic acid supplementation in preventing birth defects in high and low prevalence areas.[24] It was conducted in Northern China (prevalence of 50-60 NTD/ 10,000 births) and in Southern China (prevalence of 10/ 10,000 births) during 1993-1995. In Northern China women taking the supplement at least 80% of the time had a relative risk reduction of 85%. Overall, the rate was reduced in both regions - Northern China decreased to 33/10,000 births and Southern China decreased to 8/10,000 births.[24] This study was evidence of the benefits of folic acid alone, regardless of environment, ethnicity, genetics, health, or nutritional status.

Two recent studies showed the effectiveness of community campaigns for folic acid awareness. One study in Virginia consisted of a year long community folic acid media campaign, involving printed posters, brochures, information

cards, and banners. They even solicited help from grocery stores to promote foods high in folic acid. Random post-intervention telephone surveys showed an increase in awareness from 31% at baseline to 75% of people surveyed.[25] However, this study did not measure behavior change.

A similar media campaign was conducted in the Netherlands and did include an assessment of behavior change.[26] This study compared rates of awareness and behavior change among women of low and high socioeconomic groups. Women in the low SES reported a change in the use of folic acid from 17.5% at baseline to 46.9% post-intervention. The higher SES group reported a change from 39% at baseline to 70% post-intervention use. The disappointing outcome of the study is that only 17% of low SES women and 32% of high SES women took folic acid for the advised periconceptual period of time.[26]

Much of this intervention will use tools from the CDC collaborative campaign that was designed to educate all women with pregnancy potential about the benefits of taking folic acid. The CDC used extensive health communications research to determine the best methods to use in their multi-dimensional campaigns. They targeted women in various stages of readiness for pregnancy - contemplators and non-contemplators. Their research found that Hispanic women were more open to the idea of pregnancy and resembled the contemplators.[1] The working group has since published a resource guide, "Preventing Neural Tube Birth Defects: A Prevention Model and Resource Guide."[27] The manual is a step-by-step guide to planning, implementing, and evaluating a folic acid awareness program. It has samples for television and radio ads, public service

announcements (PSA), posters, and brochures. Many of the tools are also available in Spanish. The CDC is currently in the process of evaluating its national campaign.[1]

The CDC manual highlights a program implemented by the Georgia Department of Human Resources in its public health departments. The program included a pre and post intervention survey assessing women's knowledge, attitudes, and behaviors; educational brochures, posters, videos, and refrigerator magnets, and distribution of a three month supply of folic acid. Evaluation results were not yet available for this program.[27] A similar program will serve as the basis for the intervention and control groups in this program plan.

Many of the campaigns have shown some success in raising awareness among the general population but few have shown long-lasting effects on behavior changes. With the exception of the CDC, very few have implemented culturally specific elements. In order for programs to be more effective and successful in the Hispanic community, they should be culturally relevant; many models used in health promotion are based upon middle-class white Americans.[28]

Certain cultural factors are common to many Hispanics. *Familism* or the importance of family in everyday decision-making is a central tenet of Latino culture.[29] Family is usually involved in every aspect of a person's life, and he or she would think of family issues prior to making most decisions. Women in the family generally are the caretakers and decide when medical care is needed. Men are usually in charge of the finances, transportation, and final decisions about health care. Male support is essential to the success of any intervention involving

the family. Sometimes called *machismo*, this type of male dominance can favorably affect the outcome of a program if the male is included and agrees with the basic goals. [30]

Other personal factors such as *personalismo* (personal relationship with people within an institution), *respeto* (deference for authority), and *confianza* (long-developing trust) are also important.[29] Programmers and staff at public health agencies should work towards becoming more culturally competent by being aware of these factors and should try to incorporate them into all programs.

Other factors to take into account when planning programs for Latinos are the level of acculturation and the socioeconomic status of the community.[28] These concepts are important in that they determine how much the program should be adapted to include the above cultural norms. If a Mexican-American is highly acculturated into mainstream American society, the more common models and theories may be more likely to work. However, if many of the residents of a community are newly immigrated, then new models that incorporate more culturally relevant interventions must be designed.

Finally, language is probably the most important aspect of any contact with the Latino community. Having translators available for people who cannot speak English is essential to the success of any program. Better still, having bicultural and bilingual community participants would enhance the effectiveness of the message.[9] Having materials such as posters and brochures printed in Spanish is also helpful. (See Figure 3.)

One successful program used the LHA approach to engage the Latino community. The funding organization was a group of Latino health and human service providers who spearheaded a coalition of community members to form the Latino Health Advocacy Program.[31] The program was designed to improve access for Latinos to the various public service agencies. The heart of the group was the lay health advisors or promotoras/promotores, who were members of the community trained to serve as a bridge between the community and the agencies. They were successful in providing *personalismo* that made the community members more comfortable and more likely to access the available services.[31]

Another program evaluated the use of lay health advisors (LHA) for diabetes education in a Hispanic population.[32] Sixty-four patients were enrolled in a multi-session diabetes education program and were randomized into the LHA intervention group or the non-LHA intervention group. The LHA were bicultural, bilingual persons who resided in the community and had worked with the diabetes program previously. The LHA provided support to the patients and their families, translation services, accompaniment to educational sessions, and reminders for upcoming appointments. The people who completed the program had improved knowledge and self-care practices, as well as lower glycohemoglobin levels. About 80% of the people with a LHA completed the program, while only 47% without a LHA completed the program. This difference was highly significant with a p value of 0.007. Disappointingly, the independent effects of the LHA on the above factors were not significant. This was most likely due to insufficient power to detect a difference, since the number of people studied was small.[32]

In this intervention I plan to use elements from some of the programs mentioned above. I will integrate the lay health advisor approach with a health department based awareness campaign targeted to Hispanic patients. The LHA will conduct brief educational sessions with the patients in order to influence the use of folic acid. This type of intervention has not been documented in the literature. By tailoring the program for the target population, my hypothesis is that a long-lasting behavior change will be more likely.

# Program Goals and Objectives

**Goals:**

- To improve the health of Hispanic mothers and children in Columbus County
- To reduce morbidity and mortality for Hispanic infants in Columbus County by reducing the number of neural tube defects. *

**Objectives:**

❖ **Outcome:**

- To increase the proportion of Latinas in Columbus County who understand the importance of folic acid in preventing neural tube defects
- To increase the proportion of Latinas taking at least 400 micrograms of folic acid daily by supplement or diet by 50% by 1 year after program implementation as measured by post-intervention surveys

❖ **Process:**

- To train a lay health advisor to conduct educational programs at the Columbus County Health Department
- To educate Hispanic families about the direct link between intake of folic acid (via diet or supplement) and neural tube defects
- To educate Hispanic families about which foods contain folic acid by fortification and naturally
- To form a Folic Acid planning committee
- To provide posters and brochures about folic acid in the waiting area of the health department in Spanish and English

**Activities:**

- Hire a natural helper from the Hispanic community in Columbus County to serve as a lay health advisor
  - Provide a cultural competency training day for all Columbus County Health Department staff members
- Train the lay health advisor and staff involved in the intervention about folic acid and neural tube defects
- Obtain folic acid posters, brochures, and educational materials from the CDC
- Provide free samples of folic acid supplements for any Hispanic families who cannot afford them through the family planning clinic
- Develop a survey assessing knowledge about folic acid and behavior related to obtaining sufficient amounts of folic acid to prevent NTD

* Due to small numbers of infants born with NTD in Columbus, this goal could only be measured statewide.

# Implementation Plan

## Intervention

The intervention will focus on educating Hispanic women and their families about the benefits of taking folic acid to prevent neural tube defects. Because of the emphasis on family in Hispanic culture, I plan to direct the intervention toward all the members of the family, including the males. The intervention will target Hispanic women aged 18-45 who come to the health department seeking any health services, including well-child care, prenatal care, family planning services, nutrition services, the Women's, Infant's and Children's Program (WIC), or primary care. It will also target Hispanic men in the same age group who come for primary care services or for any services with their children or partners. These age groups will be used because they are most representative of adults of childbearing age. Eligibility for the intervention will be determined by self-identification as Hispanic/Latino on health department forms or when prompted by staff members.

The intervention will last for six months. Including planning and evaluation, the entire program will be planned for an 18-month period. Although the health department has not completed its needs assessment and has not determined how many Latinos visit the health department yearly, I will use the estimate of 480 eligible adults (60% of the 800 persons who use the health department) per year. Spread over six months, half that number would be 240 adults aged 18-45. This will be the targeted sample size and will serve as the basis for the budget and timeline.

The patients will be placed consecutively into intervention groups, alternating between the general intervention and the intensive intervention. All patients will receive a pamphlet explaining the benefits of folic acid, a reminder magnet with details on how to obtain free samples of vitamins with folic acid from the health department, a pre-test testing knowledge about folic acid and behavior regarding the taking of an adequate amount of folic acid, and a six month follow up survey. There will also be folic acid educational posters in the waiting area and at the nurse's stations in each department. The posters will be in Spanish and in English.

The intensive intervention group will receive a short intensive educational session with a lay health advisor. These sessions will take place during their usual interview by the nurse in the department they are visiting. The lay health educator will take five minutes to discuss folic acid and its benefits. She will have a checklist of major talking points including:

- Description of NTD with visual aids
- Prevention of NTD with the vitamin folic acid
- Sources of folic acid including multivitamins, fortified foods, and natural foods
- Importance of taking folic acid even when not planning a pregnancy
- Importance of taking folic acid periconceptually
- Availability of multivitamins with folic acid at the health department
- Availability of nutrition services to increase folic acid intake in diet

The sessions will be conducted in Spanish if necessary for comprehension by the patients. The LHA will provide the most culturally specific part of the intervention. By having one-on-one sessions with patients, they will be incorporating the shared values of *personalismo* and will hopefully gain *respecto* and *confianza*. Because Latinas are more likely than other women to be contemplators of pregnancy, they may be more attentive to the message, especially a message involving the health of a child.[1] Inclusion of the males in the educational program is also non-traditional and culturally specific, especially considering a message that is usually geared toward women only.

**Table I: Description of General and Intensive Interventions**

| ***General Intervention (120)*** | ***Intensive Intervention(120)*** |
|---|---|
| - Check in at front desk/eligibility check<br>- Fill out pre-test survey/consent form<br>- Given pamphlet and reminder magnet<br>- 6 months follow-up survey<br>- Folic acid tablets available for 6 months supply if needed | - All steps in General Intervention<br>- 5-minute educational session with lay health advisor<br>- Nutrition counseling services made available |

## Staff

The program will require the help of much of the staff at the health department. The first step in planning will require the formation of a planning committee. The **Folic Acid Education committee** will be chaired by the project coordinator and will meet weekly in the initial planning stages and then monthly

during the intervention and evaluation. The committee will provide support to the project coordinator and the lay health educator, as well as generate ideas and help solve problems. The committee could include staff members from each department in the health department, a physician, a nutritionist, the translators, patients, community leaders and other members of the Hispanic community. Community members will be selected based upon interest in the project. The committee will serve as the liaison between the health department and the community and will provide culturally appropriate guidance.

The **project coordinator** will provide leadership and supervision for the overall operation of the program. Her tasks include tailoring the program to fit the health department, hiring the lay health educator, supervising the implementation of the intervention, supervising the analysis of the data from the surveys, searching for program funding, and delegating tasks to other members of the committee and the health department staff. The coordinator at Columbus County would most likely be the Assistant Health Director but could also be one of the nutritionists if they have training in health education.

The ideal **lay health advisor** would come from the Hispanic community in Columbus County or surrounding counties. The person would need to be bilingual and have an educational level that would allow him/her to communicate effectively in both written and oral communication. The person would preferably be female since the topic may be more acceptable discussed by a woman. She will be trained by the coordinator to administer surveys and implement the program. She will also attend educational seminars given by the nutritionist on

nutrition and folic acid supplementation. Her duties will include administering the pre-test survey in Spanish or English, the five-minute educational sessions with eligible Hispanic clients, administrative duties such as tracking patients included in the study and insuring appropriate follow-up, conducting the evaluation and other tasks assigned by the program coordinator.

In addition to serving on the Folic Acid education committee, the **nutritionist** will be very involved with the implementation of the program. She may even serve as project coordinator if she has the appropriate background and sufficient time to devote to the project. She will provide most of the training for the LHA on folic acid supplementation and nutrition related to obtaining a diet rich in folic acid. She will also conduct nutritional sessions with patients to evaluate the amount of folic acid in their diet and then recommend culturally based changes. Being bilingual in Spanish and English would be desirable in order to communicate with patients directly and to check the validity of educational tools and surveys.

The **departmental nurses** will be key participants. They will be responsible for contacting the folic acid educator to come to their department. The nurses will also receive folic acid training by the nutritionist to use with their English-speaking patients.

The **front desk staff** will be the first line of contact for the patients. They will determine eligibility for the intervention by checking the charts for their self-identified ethnicity or asking the patient directly. Generally, there is a bilingual

staff member available at the front desk. If not, a **translator** will be called to explain the program and administer the survey.

All staff members, including physicians, nurse practitioners, and physician assistants will receive a one-day seminar on serving the Hispanic community in a culturally competent manner. The training, provided by the Department of Health and Human Services Office of Minority Health, will focus on the health problems affecting the Hispanic community. The participants will learn about specific cultural practices and beliefs. Also, the results of the needs assessment conducted by the health department will be discussed so that specific community needs can be addressed.

The North Carolina Folic Acid Council will also conduct a seminar focusing on folic acid and neural tube defects. All staff members directly involved with the administration of the program will be required to attend this on-site meeting. The intervention program will be described in detail at this meeting, highlighting the culturally specific elements of the program.

## Timeline and Activities

| Dates | Activity |
|---|---|
| Month 1 Week 1 | Monthly Planning meeting with staff only<br>Advertise in community for participants<br>Begin search for LHA<br>Begin applying for grants |
| Month 1 Week 2 | Contact Office of Minority Health, DHHS to conduct competency training for staff<br>Contact DHHS, pharmaceutical companies, pharmacies, March of Dimes, or NC Folic Acid Council about free folic acid samples |
| Month 1 Week 3 | Supplement needs assessment with information specific to the Hispanic community |
| Month 2 Week 1 | Monthly planning meeting with staff and community<br>Start developing reminder magnets with info on how to obtain samples of folic acid |
| Month 2 Week 2 | Key informant interviews within health department |
| Month 3 Week 4 | Deadline for hiring LHA |
| Month 4 Week 1 | One day competency training for staff<br>Begin training of LHA by nutritionist and project coordinator |
| Month 4 Week 2 | Obtain posters, pamphlets, and educational materials from CDC in Spanish and English |
| Month 5 Week 1-4 | Develop written/oral survey in Spanish and English and pilot test in health department<br>Develop consent forms<br>Training by NC Folic Acid Council for nurses, LHA, and other staff<br>Key informant interviews by LHA in the community |
| Month 6 Week 1 | Start general educational campaign, including posters in waiting area, pamphlets and reminder magnets |
| Month 7 Week 1-<br>Month 12 Week 4 | Start intervention<br>Start pre-tests and consent forms |
| Month 13 Week 1 | End intervention, continue general campaign<br>Start monthly evaluations |
| Month 19 Week 1 | Send surveys to UNC-CH statistician for analysis |
| Month 24 | Evaluation results |

## Budget

### Personnel:

| Title | % time | Salary (per year) | Time on project | Total |
|---|---|---|---|---|
| Project coordinator | 25% | $ 50,000 | 18 months | $ 18,750 |
| Lay health advisor | 100% | $ 35,000 | 18 months | $ 52,500 |
| Nutritionist | 20% | $ 35,000 | 12 months | $ 7,000 |
| Front desk staff (2) | 10% | $ 20,000 | 6 months | $ 2,000 |
| Nurses (7) | 5% | $ 35,000 | 6 months | $ 6,125 |
| Translators (2) | 5% | $ 25,000 | 6 months | $ 1,250 |
| Consultant fee for statistician | | $ 5,000 | | $ 5,000 |
| TOTAL | | | | $ 92,625 |

The project coordinator will spend a variable amount of time on the project, more in the beginning (50% time) and less during the intervention (10%). She has other duties within the health department and will rely heavily on the LHA. The LHA salary will depend upon educational level and experience. It may be as low as $20,000 and as high as $35,000. The nutritionist's time varies but averages to 20%. She will only work during the planning and implementation phases, not the evaluation phase. The front desk staff is included because their duties in the study will extend beyond their regular duties and should be supported by the program during the six-month intervention phase. The nurses and translators will only spend six months on the project. Competency training and nutritional training are considered a part of their usual continuing education for the health department.

### Fringe benefits:

These costs will be 10% of total cost ($87,625), only including time spent on the project and not including consultant fees. The total for fringe benefits will be $8,763.

**Supplies:**

| Type | Cost |
|---|---|
| Posters from CDC in Spanish and English | In-kind |
| Pamphlets from CDC in Spanish and English | In -kind |
| Refrigerator Magnet (500 at $1.00/magnet) | $ 500 |
| 500 Survey Copies ($0.04/copy) | $ 20 |
| 30 Folic acid training manuals ($0.04/copy – 50 pages/manual) | $ 60 |
| 120 bottles of folic acid (250 tablets/bottle for 6 months supply at $3/bottle) | $ 360 |
| Envelopes for mailing our 6-month survey | $ 10 |
| 240 Stamps ($0.34/stamp) | $ 82 |
| Long distance calls ($50/month) | $ 900 |
| TOTAL | $1,932 |

Posters and pamphlets will be received free of charge from the CDC. The biggest cost will be magnets, long distance telephone charges, and folic acid supplements. Perhaps the magnets, training manuals and vitamins could be donated in-kind.

**TOTALS**

| | |
|---|---|
| Personnel | $ 92,625 |
| Fringe benefits | $ 8,763 |
| Supplies | $ 1,932 |
| **GRAND TOTAL** | $ 103,320 |

This budget represents the total amount needed for the operation of the program with very few in-kind donations. Many of the services provided by the front desk, the nurses, the translators, and the nutritionist will be a usual part of their job and may not need to be budgeted. This may bring the cost down considerably. We anticipate that the folic acid supplements will be provided in-kind from a pharmaceutical company or pharmacy. If not, they may have to be purchased by the health department.

## Evaluation Plan

Evaluation of the program will occur on two levels. The first is the implementation evaluation. The design will be quasi-experimental with non-randomized comparison versus intervention groups. The comparison group will be the general intervention group. They will be compared to the intensive intervention group for changes in knowledge and behavior as documented by the pre- and post-intervention surveys. The surveys will be developed by the project coordinator, the LHA, and the nutritionist, using the CDC survey as a model.[27] It will include an assessment of the client's knowledge about the link between folic acid and neural tube defects, knowledge of sources of folic acid, and behaviors that include taking adequate amounts of folic acid daily. For males it will be adapted to ask whether the female of childbearing age in their household takes folic acid. The survey will be developed in Spanish and English and pilot tested in the health department for assessment of validity.

Each person will only be tested once and will not receive the intervention more than once. The surveys will be conducted six months apart. The hypothesis is to detect at least a 25% difference between the two groups post-intervention and a 50% increase in baseline knowledge and behavior in the intervention group. The analysis of the surveys will be conducted by the North Carolina State Center for Health Statistics.

The sequence of events is as follows: When a client comes to the health department, he or she will be screened for eligibility by the front office staff. If eligible, he/she will be given a written consent form and a pre-test survey in the

language of his/her choice. The survey will have no identifying information on it. However, it will be consecutively numbered and linked to a master list with labels on it. This list will track receipt of the intervention, identify group assignment, and determine if the patient has previously received the intervention. If the client has not filled out the information by the time of the educational session, the educator will go over the consent form and pre-test orally.

The post-intervention survey will be mailed to the clients' home addresses in monthly batches, six months after the intervention. The survey will be marked to identify comparison versus intervention group, and each number on the survey will correspond to the master list. If no completed survey is received within a month of the mailing, patients will be contacted by the LHA by telephone. This extra step will likely improve the study retention rate. If the person does not return the form or cannot be reached by telephone, they will be considered lost to follow-up.

Several process evaluation techniques will be used. The LHA will be given a checklist of talking points to cover and will determine if the patient understands each one before the end of her discussion. Another process evaluation will be comparison of clinic records with the number of surveys collected. The program coordinator will review clinic visits on a monthly basis. She will determine how many Hispanics visited the health department and compare that number to the number of pre-test surveys delivered by the advisor. Thus, she will be able to ascertain how many people are receiving the educational program and how many are not. If there is a large discrepancy, efforts to include the missed clients will

have to intensify. Nurses will be asked to provide the educational sessions during their next visit with the patients.

The analysis of the surveys will be completed by the North Carolina State Center for Health Statistics within six months after the evaluation is completed. The project coordinator and committee will review the data and write a summary report. The report will be given to the CDC and a manuscript based on the report will be submitted for publication in a national or state journal.

## Anticipated Barriers

The major anticipated barrier is the language barrier between most of the staff and the patients they serve. We will overcome this barrier by heavily recruiting throughout Columbus County for a bilingual LHA. If we identify more than one person, we can recruit them into the project or other activities at Columbus County Health Department. Also, finding information in Spanish may be difficult. We will work directly with the CDC to revise needed materials that they do not provide in Spanish. We will also work with the State Health Department Office of Minority Health if needed.

The second barrier is financial. We will need funding from outside sources in order to provide the training for staff, hire a new staff member, expand the jobs of existing staff members, and provide folic acid samples to the patients. The health department will apply for grants from the March of Dimes or other organizations focused on prevention of NTD.

Also, the program is labor-intensive and expensive and may undergo criticism for using scarce resources for an educational campaign to increase knowledge and change behavior for one nutrient.[16] However, the costs for no intervention in this population are much higher than the costs of this program, considering the lifetime cost of caring for a person with NTD is over $500,000.[1]

The next two barriers are related to each other – lack of time and lack of buy-in from staff. Depending upon the daily volume of Latinos, the educator may not have enough time to see everyone who is eligible. Similarly, the nutritionist may have other clients, and the nurses may have other patients waiting and other tasks to do. The whole program will require considerable buy-in from the staff in order to work. If they feel that this is just "one more thing to do," they will be less than enthusiastic about the program. With all the initial training and an explanation of the need for the reduction of neural tube defects in this population, we anticipate that they will be cooperative. Given the difficulty in sustaining such an intense intervention for a long period, the initial program will only run for six months and then will be evaluated for effectiveness.

## Ethical Considerations

Several ethical issues must be considered in the implementation of this program. The most obvious is the use of human subjects for research. While the evaluation is not a formal research study, it does have some of the same components of a study. We will obtain approval from an institutional review board (IRB) either through the University of North Carolina or the state IRB. The

clients will sign an informed consent form when they complete the first pre-test survey and meet with the LHA. They will be informed that the study results, although anonymous, may be used outside of the health department in national, state or private publications. Also, they should be informed that their participation in the evaluation is voluntary; they can and will still benefit from the educational sessions and services of the health department.

The health department must also respect patient autonomy, understanding that the patient has ultimate control over their attitudes and behaviors. However, the health department is bound by its duty to serve the needs and to improve the health of the community. This involves the ethical principle of beneficence or benefiting others.[33] This principle is central to the mission of most health departments, including Columbus County.

The last important principle is justice, specifically distributive justice.[33] Many Hispanics do not have equal access to health care or health information due to language barriers, cultural differences, and economic differences. In order to provide equal access, they may require more specialized services such as availability of translators. Providing culturally appropriate services does not mean a group gets preferential treatment; it means they get the same treatment but tailored to their individual situation.

## Summary

The program plan outlined above will serve as a pilot program for the Columbus County Health Department. If similar programs were implemented statewide and effectively changed the behavior of 50% of Hispanic women in the state, two fewer babies per year in North Carolina would have a NTD.[†]

The program will serve the dual role of preventing morbidity and mortality for Hispanic babies in the county and providing more culturally competent care for its Hispanic residents. If successful, the culturally specific LHA approach can be used for other educational issues in the health department, perhaps even expanding into the community. The program will serve as the continued evolution of the health department's commitment to providing excellent care for all of its county's citizens.

[†] If there were 379,000 Latinos with a birth rate of 16.1/1000, then there would be 6101 births per year. At the general population rate of NTD of 10/10,000 (the Hispanic rate is most likely higher), there would have been 6 Hispanic babies born with NTD in 2000. Considering the effectiveness of folic acid at 50-70% and a behavior change in 50% of women, only 4 Hispanic babies would have NTDs.

# References

1. Mersereau, PW. Preventing Neural Tube Birth Defects: A National Campaign. *Small Talk* 2000; 12(2): 1-2, 4-5. On National Center for Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention website http://www.cdc.gov/ncbddd/folicacid/smalltalk.htm (12 Apr 2002)
2. North Carolina Center for Health Statistics. North Carolina Birth Defects Monitoring Program, Surveillance Report. Reported July 2000 http://www.schs.state.nc.us/SCHS/about/programs/bdmp.html ( 11 Apr 2002)
3. United States Census Bureau. Census 2000 Redistricting Data (Public Law 94-171) Summary File, Matrices PL1 and PL2. On http://factfinder.census.gov/home/en/pldata.html (11 April 2002)
4. North Carolina Department of Commerce, Economic Policy and Research Division, Economic Development Information Systems, Section on Columbus County. http://medis.commerce.state.nc.us/countyprofiles/ (12 Apr 2002)
5. Hilda Memory, Assistant Health Director and Nurse Manager for Columbus County Health Department. Personal communication on 20 April 2001.
6. Faith Action and the International House. 2001 Hispanic Population Estimates for North Carolina Counties. On website http://faithaction.com (11 Apr 2002)
7. North Carolina Center for Health Statistics. Health Statistics at the State Center. Updated 1 April 2002 on http://www.schs.state.nc.us/SCHS/healthstats (12 Apr 2002)

8. Manson AB, Borg A, Brewer J, Lutton M, Torres Y. Latina Reproductive Health in North Carolina: Demographics, Health Status, and Programs. OMH No.20 North Carolina Office of Minority Health, Division of Public Health, NC Department of Health and Human Services, 1999.
9. Delgado JL, Metzger R, Falcon AP. Meeting the Health Promotion Needs of Hispanic Communities. *American Journal of Health Promotion* 1995; 9(4): 300-11.
10. US Department of Health and Human Services, Office of Disease Prevention and Health Promotion. Healthy People 2010, Chapter 16-Maternal. Infant, and Child Health. November 2000, online edition http://www.health.gov/healthypeople/default.htm (12 Apr 2002)
11. Centers for Disease Control and Prevention. Surveillance for Anencephaly and Spina Bifida and the Impact of Prenatal Diagnosis –United States, 1985-1994. August 25, 1995; *MMWR* 44(S-4):1-13.
12. Hendricks KA, Simpson JS, Larsen RD. Neural Tube Defects Along the Texas-Mexico Border, 1993-1995. *American Journal of Epidemiology* 1999; 149(12): 1119-1127.
13. Botto LD, Moore, CA, Khoury MJ, Erickson JD. Medical Progress: Neural-Tube Defects. *The New England Journal of Medicine* 1999; 341(20): 1509-1519.
14. Becker, MH. The Health Belief Model and Sick Role Behavior. *Health Education Monographs* 1974; 2: 409-419.

15. Janz NK, Becker, MH. The Health Belief Model: A Decade Later. *Health Education Quarterly* 1984; 11(1): 1-47.

16. Kloeblen AS & Batish SS. Understanding the Intention to Permanently Follow a High Folate Diet among a Sample of Low-income Pregnant Women According to the Health Belief Model. *Health Education Research* 1999; 14(3): 327-338.

17. Bartholomew LK, Parcel GS, Kok G, Gottlieb NH. Theories in Health Education and Promotion. In Bartholomew LK, Parcel GS, Kok G, Gottlieb NH. *Intervention Mapping: Designing Theory and Evidence-Based Health Promotion Programs* (pp.27-129). Mountain View, CA: Mayfield Publishing, 2001.

18. McGuire WJ. Attitudes and Attitude Change. In G. Lindzey & E. Aronson (Eds.), *The Handbook of Social Psychology: Vol,2. Special Fields and Applications* (3rd ed., pp. 233-346). New York: Knopf, 1985.

19. Swider SM. Outcome Effectiveness of Community Health Workers: An Integrative Literature Review. *Public Health Nursing* 2002; 19(1): 11-20.

20. Eng E, Parker E, Harlan C. Lay Health Advisor Intervention Strategies: A Continuum from Natural Helping to Paraprofessional Helping. *Health Education and Behavior* 1997; 24(4): 414. Adapted from Service C, Salber E. (Eds.) *Community Health Education: The Lay Health Advisor Approach.* Durham, NC: Duke University Health Care System, 1979.

21. Eng E, Parker E, Harlan C. Lay Health Advisor Intervention Strategies: A Continuum from Natural Helping to Paraprofessional Helping. *Health Education and Behavior* 1997; 24(4): 413-417.

22. Zuvekas A, Nolan L, Tumaylle C, Griffin L. Impact of Community Health Workers on Access, Use of Services, and Patient Knowledge and Behavior. *Journal of Ambulatory Care Management* 1999; 22(4): 33-44.

23. Institute of Medicine. Report of the Institute of Medicine Food and Nutrition Board, Standing Committee on the Scientific Evaluation of Dietary Reference Intakes. Washington, DC: National Academy Press,1998:8.

24. Berry RJ, Li Z, Erickson JD, Li S, Moore CA et.al. Prevention of Neural-Tube Defects with Folic Acid in China. *The New England Journal of Medicine* 1999; 341(20): 1485-1490.

25. Broome K. Folic Acid Campaign and Evaluation- Southwestern Virginia, 1997-1999. *MMWR* 1999; 48: 914-917.

26. De Walle HEK et.al. Effect of Mass Media Campaign to Reduce Socioeconomic differences in Women's Awareness and Behaviour Concerning Use of Folic Acid: Cross Sectional Study. *BMJ* 1999; 319: 291-292.

27. Burke B, Daniel KL, Latimer A, Mersereau P, Moran K, et.al. Preventing Neural Tube Birth Defects: A Prevention Model and Resource Guide. Atlanta, GA: Centers for Disease Control and Department of Health and Human Services, 1999.

28. Castro FG, Cota MK, Vega SC. Health Promotion in Latino Populations: A Sociocultural Model for Program Planning, development, and Evaluation. Chapter in Promoting Health in Multicultural Populations: A Handbook for Practitioners. By Robert Huff and Michael Kline. Thousand Oaks, CA: Sage Publications Inc., 1999

29. North Carolina Office of Minority Health, Division of Public Health, NC Department of Health and Human Services brochure. Important Values the Affect How Health Services are Perceived and Received. From COSSMHO Curriculum: Delivering Preventive Health Care to Hispanics. Washington, D.C. (date not reported on form)

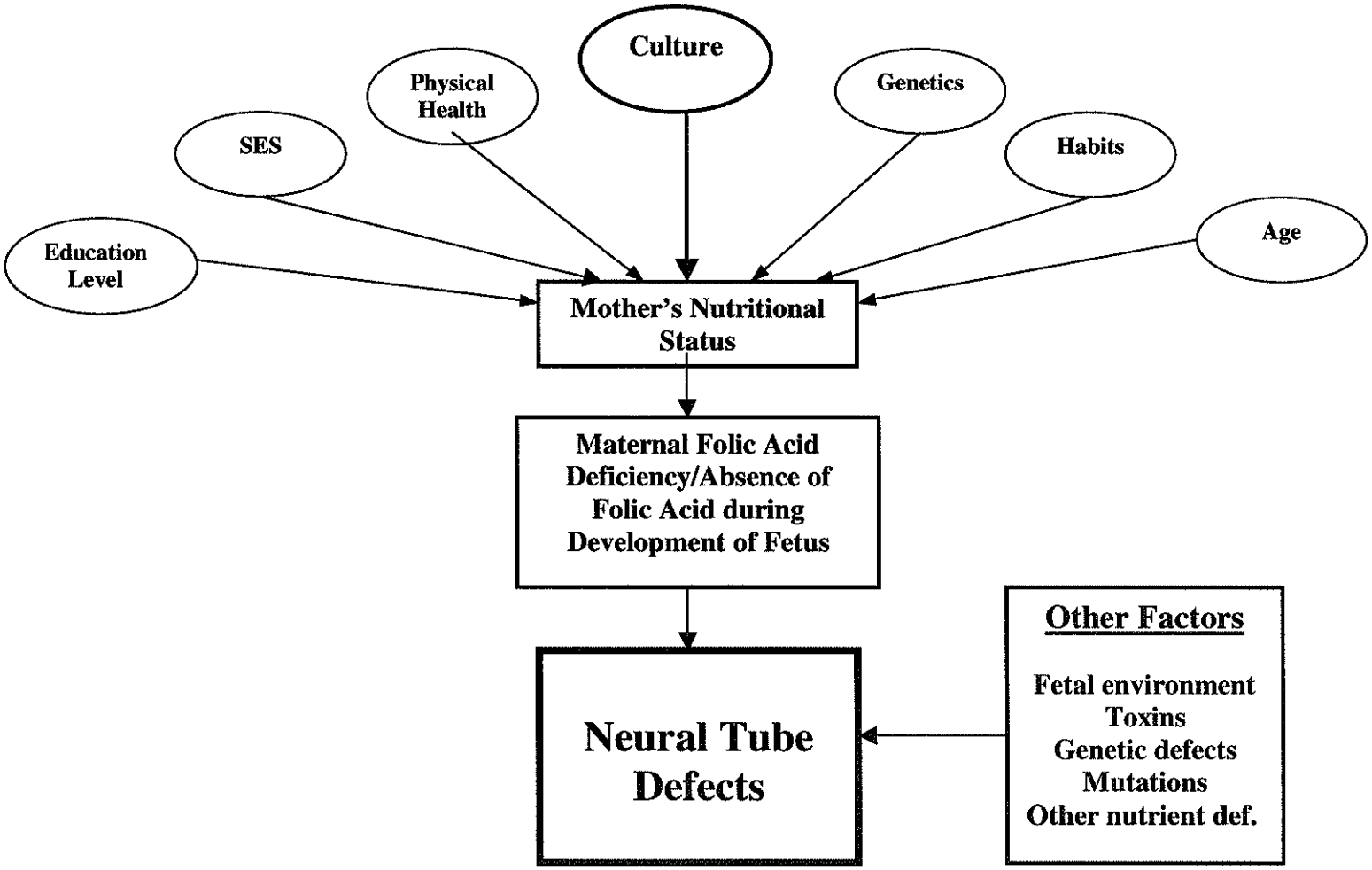
30. Caudle P. Providing Culturally Sensitive Health Care to Hispanic Clients. *Nurse Practitioner* 1993; 18(12): 40-51.

31. Baker EA, et.al. The Latino Health Advocacy Program: A Collaborative Lay Health Advisor Approach. *Health Education and Behavior* 1997; 24(4): 495-509.

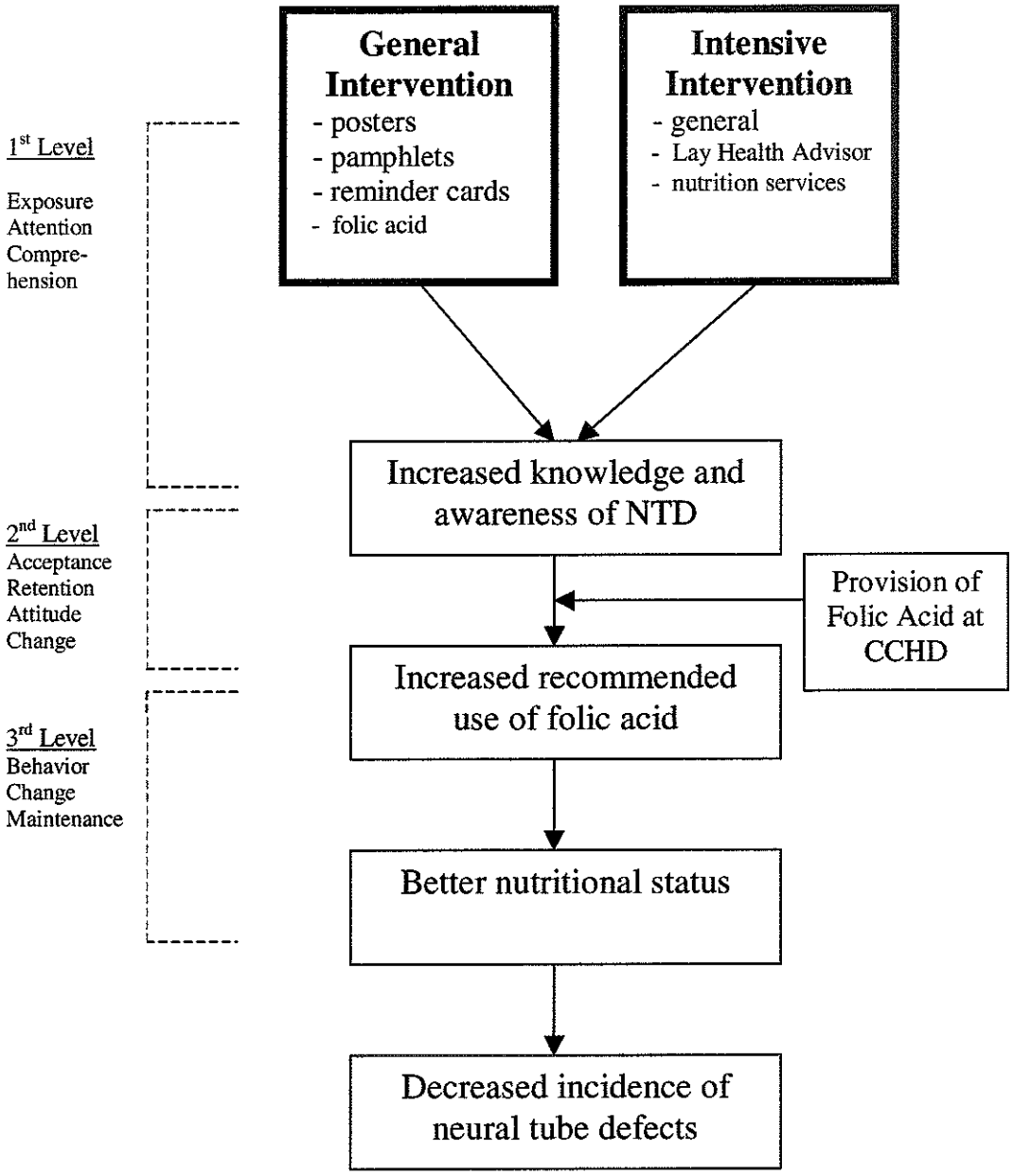
32. Corkery E et al. Effect of a Bicultural Community Health Worker on Completion of Diabetes Education in a Hispanic Population. *Diabetes Care* 1997; 20(3): 254-257

33. Newman DL & Brown RD. Ethical Theories and Principles. In, Newman DL & Brown RD, *Applied Ethics for Program Evaluation*, 1996, pp. 17-54. Newbury Park: Sage Publications.

# Figure 1: Model of Problem



# Figure 2: Model of Intervention



# Figure 3: Influences on Attitudes and Behavior